

DOCUMENT RESUME

ED 314 680

CG 022 215

AUTHOR Pynoos, Jon; Ohta, Russell J.
TITLE The Caring Home Program: In-Home Interventions for
Alzheimer's Disease Patients and Their Caregivers.
PUB DATE 89
NOTE 12p.
PUB TYPE Reports - Descriptive (141) -- Reports -
Research/Technical (143) -- Speeches/Conference
Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Alzheimers Disease; *Caregivers; *Interdisciplinary
Approach; *Intervention; Patients; *Program
Effectiveness

ABSTRACT

The home is clearly the major setting in which care is provided to individuals suffering from Alzheimer's disease. The Caring Home Program was a multi-disciplinary program designed to complement existing efforts to assist caregivers (N=12) with the in-home care of Alzheimer's disease patients. The program components consisted of an assessment of patient level of functioning and problems experienced by the caregiver, an independent assessment of the home environment, the team identification of target areas for intervention, the implementation of specific caregiver-selected interventions, and the evaluation of intervention effectiveness over several months. Evaluation of the program indicated that the majority of interventions which were initially effective were reported by caregivers as still effective approximately 7 to 9 months later. It was evident even with careful professional assessment of patient and caregiver needs, and caregiver input in the selection of specific interventions from the implementation, that some interventions may be ineffective from the outset. The apparent reasons which emerged for intervention ineffectiveness and their implications for minimizing such ineffectiveness in the future are instructive. (ABL)

* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *

The Caring Home Program: In-Home Interventions for
Alzheimer's Disease Patients and their Caregivers¹

Jon Pynoos, Ph.D.²

Russell J. Ohta, Ph.D.³

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

☒ This document has been reproduced as
received from the person or organization
originating it.
☐ Minor changes have been made to improve
reproduction quality.

• Points of view or opinions stated in this docu-
ment do not necessarily represent official
OERI position or policy.

"PERMISSION TO REPRODUCE THIS
MATERIAL HAS BEEN GRANTED BY

Jon Pynoos

TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)."

¹This program was supported by grants from the Andrus Foundation of the American Association of Retired Persons and the California Department of Health Services, with additional support from the Tingstad Alzheimer's Disease Research Fund.

²United Parcel Service Foundation Associate Professor of Gerontology, Public Policy and Urban Planning, and Director, Program in Policy and Services Research, Andrus Gerontology Center, University of Southern California, Los Angeles, CA 90089-0191.

³Formerly Director, the Caring Home Program. Currently Partner, Southwest Geriatric Consultation Services, 8115 N. 18th Street, #115, Phoenix, AZ 85020.

Abstract

Described is a multidisciplinary program which assessed the needs of Alzheimer's disease patients and their caregivers in the home, identified target areas for intervention, and implemented specific caregiver-selected interventions. Evaluation of the program indicated that the majority of interventions which were initially effective were reported by caregivers as still effective approximately seven to nine months later. The importance of this relative stability of initially-effective interventions despite progressive decline in patient functioning is discussed, along with recommendations for enhancing the effectiveness of interventions when first introduced.

Key Words: Dementia, Caregiving, Community-based

The Caring Home Program: In-Home Interventions for Alzheimer's Disease Patients and their Caregivers

The home is clearly the major setting in which care is provided to individuals suffering from Alzheimer's disease. Most Alzheimer's disease patients are cared for at home by their families for the majority of their illness, with the Alzheimer's Association estimating that six times as many patients are being cared for in the community as in nursing homes (Alzheimer's Disease and Related Disorders Association, 1985).

Consequently, much attention has been directed to assisting caregivers with the monumental task they face in providing this care at home. The programs which exist generally focus on providing caregivers with educational/training materials (e.g., through caregiver seminars and pamphlets), emotional support (e.g., through caregiver support groups), respite (e.g., through adult day health care), and/or direct in-home care of the patient (e.g., through home health services).

The present paper describes the Caring Home Program, a multidisciplinary program which was designed to complement existing efforts to assist caregivers with the in-home care of Alzheimer's disease patients. The program components consisted of an assessment of patient level of functioning and problems experienced by the caregiver, an independent assessment of the home environment, the team identification of target areas for intervention, the implementation of specific caregiver-selected interventions, and the evaluation of intervention effectiveness over several months.

The Participants

The participants in this program were obtained from local support groups, adult day care centers, and other agencies in the area, as well as through newspaper advertisements and press releases. In order to participate, the caregivers needed to be the primary care provider for the Alzheimer's disease patient and be residing in the same home as the patient. Furthermore, the patient must have had a complete medical examination within the previous six months (including blood and urine testing), a complete neurological examination

(including either a CT scan, PET scan, or MRI), must not have been bedridden, and must not have been severely impaired on four or more of the remaining activities of daily living (bathing, feeding, dressing, grooming, transfer, toileting, continence care).

The 12 caregivers who received program interventions and were available for follow-up consisted of 7 women and 5 men, 11 of whom were spouses of the Alzheimer's disease patient and 1 of whom was an adult child. The average age of the caregivers was 70.8 years, and they had been providing care for an average of 40.1 months. The average age of the patients was 77.3 years, and their activities of daily living (ADL) scores averaged 16.9 (possible range of 8-48, with higher scores indicating greater impairment) while their instrumental activities of daily living (IADL) scores averaged 37.2 (possible range of 8-46, with higher scores indicating greater impairment).

The Program

Patient and caregiver demographic information, along with caregiver reports of the patient's ADL and IADL functioning were obtained by telephone. This was followed by a home visit during which the frequency of patient problems, and the caregiver's reactions to them, were surveyed. This survey involved the use of the Problems and Barriers Survey, a 44-item instrument developed for this program (expanding the 29-item Memory and Behavior Problems Checklist of Zarit et al., 1980 and Zarit, 1982). An independent assessment and photography of the home environment was also conducted, using the Home Environmental Assessment Checklist also developed for this program.

After all information was obtained for each participant, the program team met to review the information. The team consisted of a psychologist, an occupational therapist, and a clinical gerontologist. Based upon the patient level of functioning, caregiver-experienced problems and reactions, and assessment of the home environment, the team identified and prioritized what it considered to be the most critical problems faced by each caregiver and generated a set of interventions for dealing with each problem. This list of problems and proposed interventions was then presented to

the caregiver for consideration and feedback. The caregiver selected those problems which he or she wanted addressed and the desired mode of intervention. These interventions were then implemented by the program team at no charge to the caregiver. A follow-up home visit was conducted approximately seven to nine months later to obtain the caregiver's assessment of the effectiveness of program interventions.

Program Effectiveness

At the follow-up, the 12 caregivers were interviewed regarding the appropriateness/effectiveness of program interventions. A total of 29 problems had been addressed for these caregivers. There were single instances of interventions for the problems of engaging in behavior that is potentially dangerous to self, and using stairs. There were two instances for the problems of forgetting what day it is, getting lost outside the home, losing/misplacing things, and feeding self, and three for the problems of long periods of inactivity, toileting, and continence care. The dominant problem addressed by the program was that of bathing self, for which there were ten instances of interventions. Chart 1 lists the caregiver-selected interventions implemented for the various problems.

Insert Chart 1 about here

Insert Table 1 about here

Data reflecting the effectiveness of program interventions are presented in Table 1. The interviews revealed that, for 19 of the 29 problems addressed (or 66% of the total), program interventions were evaluated by the caregivers as having been effective when first introduced. Furthermore, program interventions continued to be effective at the follow-up for 17 of these 19 problems (or 89% of the initially effective). As can be seen in Table 1, program interventions were most successful for certain problems. These included the ADLs

of feeding self, continence care, and bathing self, as well as the problems of engaging in behavior potentially dangerous to self, using stairs, and losing/misplacing things. The interviews with the caregivers indicated that, if introduced in an appropriate manner by the caregiver and at a point in the disease when the patient was capable of making the necessary adjustments, the interventions for these problems tended to become incorporated into the patient's and caregiver's daily behaviors and routines. For only two of the problems (or 11% of the initially effective), however, were program interventions initially but no longer effective at the follow-up. Both of these instances involved the patient's forgetting what day it is. In both cases, the intervention (a reality orientation board) was reported to have been appropriate for the patient's initial level of cognitive functioning, but became ineffective as the patient's cognitive functioning declined.

On the other hand, program interventions were deemed by the caregivers as having never been effective for 10 of the 29 problems addressed (or 34% of the total). It can be seen in Table 1 that program interventions were least successful for the ADL of toileting, as well as the problems of getting lost outside the home and long periods of inactivity. The interviews with the caregivers indicated that, at least for the problem of getting lost outside the home, the explanation for intervention ineffectiveness was clear: the identification bracelet was of the wrong length in one case, and was promptly destroyed by the patient in the other. Such a clear explanation was absent, however, for the ineffectiveness of particular interventions for the problem of patient inactivity. Although all interventions took into account the patient's past interests/hobbies, vocation, and current level of functioning, whether or not a patient actually became involved with a given intervention was basically reduced to trial-and-error. Finally, highly diverse were the explanations for the ineffectiveness of interventions designed to assist with toileting. In one case, the intervention (a raised toilet seat with attached rails) was not made available to the patient because, although it may have assisted the patient, it was difficult for the caregiver to use.

In another case, the ineffectiveness of the intervention (a long handled cleaner) appeared to have been due, at least in part, to the caregiver's lack of knowledge of how to introduce the intervention to the patient. In the third case, the ineffectiveness of the intervention (a bidet) appeared to have been due to either the caregiver's improper introduction of it to the patient and/or the caregiver's own observation that it was introduced too late in the course of the disease for the patient to adapt to it.

Discussion

The evaluation of the Caring Home Program is, at once, both instructive and encouraging. To begin with, it is evident that even with careful professional assessment of patient and caregiver needs, and caregiver input in the selection of specific interventions for implementation, some interventions may be ineffective from the very outset. Instructive are the apparent reasons which emerged for intervention ineffectiveness, and their implications for minimizing such ineffectiveness in the future.

First, caregivers may not be introducing interventions in an appropriate manner. Techniques which are gradual, persistent, and do not provoke negative reactions from the patient may need to be taught to the caregiver. This emphasizes the training responsibilities of the professional when presenting caregivers with interventions. Second, because of caregiver preference, the selection/rejection/discontinuation of interventions may not represent optimal choices for the patient. In other words, the effectiveness of interventions may be problematic because, in some instances, what appears to be best for the patient is not necessarily best for the caregiver. Open discussions with the caregiver regarding expectations and priorities may shed light on such conflicts, and counseling of the caregiver may be warranted in extreme cases. Third, interventions may be introduced at a point in the disease when it is difficult, if not impossible, for the patient to accept the change brought about by the intervention. In some cases, it appears that if the problem is assessed early enough and interventions are introduced while the patient is still capable of acquiring new patterns of behavior, the interventions stand a much better chance of being

effective.

At the same time, the evaluation of the program described is highly encouraging, particularly the finding that program interventions which were initially effective were still effective several months later for a very high percentage of problems addressed. This is especially exciting in view of the progressive cognitive, physical, and behavioral decline which is a signature of Alzheimer's disease. The results of the program indicate that this progressive decline does not necessarily mean that interventions designed to assist caregivers are of short-lived value. On the contrary, suggested is that interventions can have relatively sustained impact if they can be effectively implemented in the first place. The importance, therefore, of assuring the effectiveness of interventions when first introduced by caregivers cannot be overemphasized. Attention to patient needs, caregiver preferences, caregiver skills, and timing in the course of the disease are all critical in establishing and maintaining the effectiveness of interventions. If successful in doing this, an in-home program designed to enable caregivers to better care for Alzheimer's disease patients can have significant, enduring benefits.

References

- Alzheimer's Disease and Related Disorders Association. (1985).
Understanding and caring for the person with Alzheimer's disease.
Atlanta: Atlanta Area ADRDA Chapter.
- Zarit, J. M. (1982). Predictors of burden and distress for caregivers of senile dementia patients. Unpublished doctoral dissertation, University of Southern California, Los Angeles.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20, 649-655.

Chart 1

Program Interventions Selected by Caregivers

Problem	Intervention
Behavior dangerous to self	Non-electric shaver
Using stairs	Handrail
Forgetting the day	Reality orientation board
Getting lost outside	Identification bracelet
Losing/misplacing things	Locked security box
Feeding self	Partitioned plate, scoop dish, spork
Inactivity	Enlarged music sheet, sorting materials, picture book
Toileting	Long-handled cleaner, raised toilet seat with attached rails, bidet
Continence	Adult diaper, plastic liner
Bathing self	Grab bar, tub rail, bath seat, handheld shower hose, non-skid strips

Table 1

Effectiveness of Program Interventions at Follow-up

Problem	Frequency	Effectiveness		
		Initially Effective		Never Effective
		Continued	No Longer	
Behavior dangerous to self	1	1		
Using stairs	1	1		
Forgetting the day	2		2	
Getting lost outside	2			2
Losing/misplacing things	2	2		
Feeding self	2	2		
Inactivity	3	1		2
Toileting	3			3
Continence	3	2		1
Bathing self	10	8		2
Total	29	17	2	10